Physical fitness and performance of daily activities in persons with intellectual disabilities and visual impairment

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Chapter 4

Follow up study of physical fitness in persons with severe/profound intellectual and visual disabilities

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Abstract

Background Sufficient physical fitness and physical activity levels are important to maintain or improve health. However, for persons with (severe or profound) intellectual disabilities (SPIVD), no data are available about changes in physical fitness over time. The aim of our study was to gain insight into changes in physical fitness levels of persons with SPIVD and Gross Motor Function Classification System (GMFCS) Levels 1 and 2 over a ten-year period.

Methods Of 55 participants the modified Berg Balance Scale (mBBS), the adapted Shuttle Run Test (aSRT), the six-minute walk distance test (6MWD), body composition and waist circumference were measured. The test results were obtained from the clients' medical records. Changes in physical fitness levels were analyzed with mixed model estimation.

Results Over this ten-year period, BMI remained reasonably stable for persons with GMFCS 1 and a slight decrease (-1.2 kg/m² p=<0.05) occurred for those with GMFCS 2. Waist circumference increased (+2.9 cm p=0.05) for persons with GMFCS 1 while this remained quite stable for the GMFCS 2 group. An increase on mBBS was shown for persons with GMFCS 1 (3.7 points p=<0.001) and, for the GMFCS Group 2, mBBS remained reasonably stable. Cardiorespiratory fitness levels remained quite stable for both persons with GMFCS 1 and 2. However, low cardiorespiratory fitness levels were ascertained in persons with SIVD.

Conclusion Physical fitness remains stable in persons with SIVD over a ten-year period.

Introduction

Sufficient physical fitness and physical activity levels are important to maintain or improve health.[1] Sufficient health consequently improves well-being and quality of life.[2,3] A higher level of physical fitness improves the ability to perform activities of daily living (ADL).[4,5] However, for individuals with intellectual disabilities (ID), additional comorbidities occur twice as often compared to the general population.[6] In addition, persons with ID have a lower level of physical fitness compared to the general population,[7-9] and those with severe or profound ID (SPID) or severe or profound ID and visual disability (SPIVD) have even lower physical fitness levels.[7,10,11]

Health-related components are body composition, cardiorespiratory fitness, flexibility, muscle strength, and muscle endurance.[12] Individuals with low levels of these components are at risk for developing medical problems, chronic diseases, and mortality.[1,9,12,13] The recommended components for measuring physical fitness for persons with SPIVD and Gross Motor Function Classification System (GMFCS) levels 1 and 2[14,15] are body composition, cardiorespiratory fitness, muscle strength, and balance.[16]

The life expectancy of individuals with ID is increasing,[17,18] however, daily functioning decreases with increasing age.[19,20] Individuals with ID have low physical fitness levels over their lifetime,[7-9, 21] and the degree of dependency increases with older age.[5,22] Also, the aging of persons with ID begins at a much younger age compared to the general population,[23] i.e., persons with ID who are aged over 50 years have as many deficits as persons without ID who are aged over 70.[23] Furthermore, individuals with ID show a greater tendency toward de-conditioning and morbidity.[24]

Since no data is available for persons with SIVD about trends in time with regard to aging, it is important to investigate whether these early signs of aging also apply for this group as this may affect their frailty. Comprehensive insight into physical fitness levels of persons with SPIVD measured over several years is necessary to identify the course of physical fitness over a long-term period in order to discover which components of physical fitness should be improved and to gain insight into their need for support and care.

The purpose of this study is to gain insight into changes in physical fitness levels of persons with SPIVD over a ten-year period.

Method

Design

A retrospective study was conducted to examine the changes in physical fitness levels of persons with SPIVD and GMFCS Levels 1 and 2 over a ten-year period over pairs of years which yielded five measurement moments. All of the aggregated test results could be obtained from the clients' medical records because the physical fitness tests were a component of their regular screening.

From 2008, the participants performed, as a regular screening policy, the modified Berg Balance Scale (mBBS), the adapted Shuttle Run Test (aSRT) and the six-minute walk distance test (6MWD). These tests were always performed with at least 48 hours in between them to provide time for sufficient rest. The tests were performed with adapted protocols due to the severity of intellectual disability in combination with the visual impairment.[16] All of the participants were guided by a familiar personal caretaker and observer. The measurements of body composition and waist circumference were performed by a member of the support staff who was associated with the group of each participant.

Due to their differences in motor skills, participants with GMFCS Level 1 performed the aSRT, and those with level 2 performed the 6MWD to measure cardiorespiratory fitness. Persons with GMFCS Level 1 and GMFCS Level 2 are both able to walk without devices, however, persons with GMFCS Level 2 are limited in walking long distances, in maintaining their balance and, when climbing and walking down the stairs, they need to use the handrail which those with GMFCS Level 1 do not.[14,15]

Participants

Participants lived in a residential care facility for the profoundly and severely intellectually and visually disabled in the Netherlands. Of the residents of this facility, 65% have motor disabilities.

Inclusion criteria for using the results of the screening consisted of having a moderate, severe, or profound intellectual disability (ID) according to the ICD-10[13] and visual disabilities (‘partially sighted to blind’).[13] Participants classified according to the Gross Motor Function Classification System (GMFCS)[14,15] into Level 1 or 2 were included. The

GMFCS is a five-level system utilized to classify the severity of motor disabilities in persons with intellectual and physical disabilities.[14,15] Participants with GMFCS Level 1 can generally walk without restrictions but tend to be limited in more advanced motor skills. Participants with GMFCS Level 2 walk with slight restrictions such as being unable to spontaneously increase their speed during walking. As the physical fitness tests used in this study are intended for persons with SPIVD and GMFCS Levels 1 and 2,[16] those residents could participate in this study. The locomotor skills of residents with GMFCS Levels 3 to 5 are very limited, therefore, had to be excluded.

Exclusion criteria for performing the regular physical fitness screening consisted of mental or physical health issues that prevented the client from participating such as psychoses, depression, or other severe psychological problems including behavioural and prolonged stress; somatic diseases defined as chronic diseases and/or diseases that are not resolved in a short period of time such as osteoarthritis, osteoporosis, pneumonia, and general illness or fever; taking antibiotics; worsening of asthma or epilepsy as signified with recent insult or epileptic fits; fresh wound(s)/bruise(s) or other factors causing pain during movement; and, finally, stress as evidenced by a participant's behavior shortly prior to the date of measurement. These issues were examined and brought forward by a physician specialized in intellectual disabilities in collaboration with a health care psychologist.

The legal representatives were asked in 2008 if they gave consent for participation of the person they represented in the physical fitness screening program. Before data collection, we requested written consent from the participants' representatives for using the data obtained by the regular physical fitness screening.

Information was collected from the clients' medical records on gender, age, level of ID, level of GMFCS, and visual impairment as well as the presence of a hearing impairment, orthopedic defects, spastic paresis, and epilepsy. The degree of visual impairment was categorized as partially sighted or severely visually impaired to blind. These characteristics were determined and categorized by a physician specialized in intellectual disabilities in collaboration with a health care psychologist and described in the results section.

Ethical statement

This study was performed in accordance with the guidelines of the Helsinki Declaration.[25] The tests that were included were a component of the regular screening policy in consultation with management and client representatives of the residential care facility. All of the participants were unable to provide consent. Therefore, extra attention was given to:

1) Obtaining informed consent from legal representatives and caregivers of all of the participants for engaging in the screening program with regard to the physical fitness tests and before data collection for using the data for the present study;

2) Formulating excluding criteria and contra-indications in close collaboration with a physician specialized in intellectual disabilities and a health care psychologist for participation in the screening program and for performing the specific tests throughout the years.

3) Performing the physical fitness tests. The tests were performed in accordance with the behavioural code section entitled 'Resistance among people with an intellectual disability in the framework of the Act Governing Medical-Scientific Research Involving Humans'.[26] Consistent distress or unhappiness was interpreted as a sign of lack of consent, and further participation in the tests was reconsidered.

Measurements and Protocols

Prior to the physical fitness tests that were performed throughout the years, the observers and personal caretakers of the participants completed a checklist covering all of the exclusion criteria. Participants did not participate during that specific year or time if they exhibited any of that criteria.

Body composition

Body weight

To determine body weight, participants were requested to remove heavy clothing and shoes before standing on an electronic calibrated gauged pair of scales (Weigh plateau for wheelchairs PM-9050, Lopital Nederland BV, Oisterwijk, the Netherlands). Participants who were unable to stand independently without moving (e.g., because of anxiety) were weighed while sitting in a wheelchair.[27]

Body height

To establish body height, participants were requested to sit in a chair with knees flexed at 90 degrees. The medial malleolus and the proximal end of the tibia were palpated, and the distance (cm) between these points was measured with a measuring tape.

The participant's body height was calculated by measuring tibia length and using either of the formulas; 74.008 + (1.841 x tibia length) + (0.389 x weight) (men) or 74.008 + (1.841 x tibia length) + (0.389 x weight) - (3.787) (women). This yields a feasible and reliable (ICC 0.99) method to measure body height for persons with SIVD.[27]

Body Mass Index (BMI)

BMI was calculated for body composition. The correlation between BMI and body fat is strong, however, it varies by gender, race, and age.[28,29] A BMI between 25 kg/m² and 30 kg/m² was defined as being overweight and a BMI ≥ 30 kg/m² as being obese.[30,31] The BMI is a feasible and reliable (ICC 0.98) method to measure body composition in persons with SIVD.[27]

Waist circumference (Wcf)

To determine waist circumference, a measuring tape (Seca 201 tape measure, accurate at the 0.1 cm level, Hamburg, Germany) was used. Waist circumference was measured at the point located halfway between the iliac crest and the tenth rib. Two measurements were taken, i.e., one at inspiration and one at expiration. The average of the resulting values was used for further analysis.[27] Central obesity was defined from 102 cm for men and from 88 cm for women.[30,31] The feasibility of these body composition measurements was sufficient for persons with SPIVD with a percentage of success measurements greater than 95%.[27] The reliability of the waist circumference in persons with SPIVD was sufficient (ICC 0.97) with no significant differences between test and retest.[10]

Physical fitness performance

Modified Berg Balance Scale (mBBS)

The mBBS[32] consists of ten items. The performance on each of these items is scored on a 5-point ordinal scale (0-4 points) whereby a score of 0 denotes the inability to perform a task and a score of 4 indicates the ability to complete the task according to the established criterion. The maximum mBBS score is 40 points. If a participant did not

understand a task, that task was excluded from the total score. The feasibility of the mBBS was sufficient for persons with SPIVD with a percentage of success measurements of 92% and having sufficient test-retest reliability (ICC 0.95).[32] Further information about the mBBS, including a brief overview of the test items, is listed in Appendix A.

Adapted Shuttle Run Test (aSRT) 2007-2009

Incremental speed walking tests are effective measures of aerobic capacity in healthy persons and in individuals with chronic conditions.[33,34]

The start speed of the aSRT was 3 km/h and was increased every minute by 0.25 km /hour.[11] Any increase in speed was called a step. At the time that the test was stopped, the number of successfully completed steps represented the participant's level of aerobic capacity. Further information about the aSRT, including the aSRT-course, is shown in Appendix B.

The feasibility of the aSRT is sufficient for persons with SPIVD and GMFCS-level 1 with a percentage of success measurements of 96%.[11] Its reliability for persons with GMFCS 1 was sufficient with no significant differences between test and retest ($p<0.05$), and ICC for the test-retest was 0.96 but not in persons with GMFCS-level 2. Therefore, the aSRT was only performed by individuals with GMFCS level 1.

However, since an aSRT on the ground has limited validity in regard to the purpose of the test being to measure HRpeak,[16] the aSRT was adapted to a treadmill protocol (GTX).[11] This test is a feasible, reliable, and valid method for determining the HRpeak as well as the number of levels attained for persons with SPIVD and GMFCS-level 1.[11] Therefore, from 2010 to 2017, the aSRT measurements were performed on a treadmill (GTX).

Adapted Shuttle Run Test (aSRT) 2010-2017 - GTX

Participants walked on a treadmill with a starting speed of 3 km/hour. Every minute, the speed was increased by alternating steps of 0.3 and 0.2 km /hour to reach the next level. These levels were comparable to the levels of the aSRT.[11] The test leader had pre-programmed the treadmill with the GXT-protocol.

The feasibility of the GTX on the treadmill was sufficient for persons with SPIVD and GMFCS Level 1 with the percentage of success measurements of 86.6%.[16] The reliability of the GTX in persons with SPIVD and GMFCS Level 1 was previously reported as

sufficient ($p<0.05$, ICC 0.95). The validity of the GTX for measuring cardiorespiratory fitness was determined to be sufficient.[16] Further information about the aSRT-GTX is reported in Appendix C.

6-minute walk distance test (6MWD)

Participants with GMFCS Level 2 performed the 6MWD test on a 36-meter course that was located in a gymnasium. The participants walked six minutes at a self-chosen pace and attempted to cover as much distance as possible without running. Gymnastics instructors accompanied the participants and helped them to find their way. This adaptation was necessary due to the intellectual disability combined with visual impairment. The participants were encouraged in a standardized way. The total distance covered measured a participant's level of functional exercise capacity.

The feasibility of the 6MWD test was sufficient for persons with SPIVD with a percentage of success measurements of 96%.[11] The reliability of the 6MWD in these persons was sufficient (ICC 0.92) with no significant differences between test and retest ($p<0.05$).[11] Further information about de 6MWD, including the 6MWD- course, is shown in Appendix D.

Data preparation

The measurements were conducted by the testing over a period of ten years. Because participants have not been measured annually but monitored over the ten-year period, we clustered the monitored measurements over pairs of years in order to obtain insight into the time effect (time effect 1 is 2008-2009; 2 is 2010-2011; 3 is 2012-2013; 4 is 2014-2015; and, 5 is 2016-2017). For each participant, the mean of each outcome variable with each pair of years was determined for further analysis. In the event that no measurements were available in that two-year period, this participant was not included in the analysis for that two-year period (-9 unseen time). We scored the number of measurement moments over the ten-year period per two years of each participant. We assumed that three to five measurement moments were necessary/appropriate to gain insight into changes in physical fitness levels of the participants in this study. The number of those who withdrew was also recorded.

Data analyses

All of the statistical analyses were performed using the Statistical Package for Social Studies (SPSS) version 22 for Windows and the statistical programming language Reversion 3.4.0.[35]

Changes in physical fitness levels were analyzed with a mixed model estimation using random intercepts for participants.[36] $P < 0.05$ is considered statistically significant.

Due to different levels of motor skills, we analyzed the changes in physical fitness separately for the groups with GMFCS Levels 1 and 2.

Results

Written consent was obtained from the representatives of 84 candidates to participate in the screening program. Written consent to collect data of the physical fitness screening to use in the present study was requested from these representatives and actually received from 72 of them. Seventeen individuals had to be excluded for medical or behavioural reasons prior to the beginning of the screening program. Overall, of the 55 participants who started with the screening program, informed consent of their representatives to use these data for the present study was obtained. This group of 55 participants comprised 19 females with a mean (SD) 41.2 (11.4) years of age, with a minimum age of 16 and a maximum 62. The 36 male participants had a mean (SD) age of 38.9 (12.1) with a minimum age of 18 and a maximum of 61. In addition, 36 of the participants were classified within GMFCS-level 1 and 19 in GMFCS-level 2. The characteristics of all of the persons starting in the screening program are shown in Table 1.

Table 1. Characteristics of the participants (2008, N=55).

	Total N=55	**GMFCS-level 1** N=36 (65.5%)	**GMFCS-level 2** N=19 (34.5)
Gender, N (%)			
Male	36 (65.5%)	24 (66.7%)	12 (63.2%)
Female	19 (34.5%)	12 (33.3%)	7 (36.8%)
Age, Mean, ± SD	39.7 ±11.8	38.2 ±12.7	42.6 ±9.6
Intellectual disability, N (%)			
Moderate	3 (5.5%)	3 (8.3%)	-
Severe	44 (80%)	29 (80%)	15 (78.9%)
Profound	8 (14.5%)	4 (11.1%)	4 (21.1%)
Visual Impairment, N (%)			
Blind/severe partially sighted	31 (56.4%)	24 (66.7%)	7 (36.8%)
Partially sighted	24 (43.6%)	12 (33.3%)	12 (63.2%)
Auditory Impairments, N (%)			
Normal hearing	36 (65.5%)	24 (66.7%)	12 (63.2%)
Hearing loss	19 (34.5%)	12 (33.3%)	7 (36.8%)
Orthopedic defects, N (%)			
Present	32 (58.2%)	18 (50%)	14 (73.7%)
Absent	23 (41.8%)	18 (50%)	5 (26.3%)
Spastic paresis, N (%)			
Present	4 (7.3%)	2 (5.6%)	2 (10.5%)
Absent	51 (92.7%)	34 (94.4%)	17 (89.5%)

GMFCS: Gross Motor Functioning Classification System

Unfortunately, four participants could not participate in the screening program for the entire ten-year period: in 2011, two participants (GMFCS 1) moved outside the residential care facility; in 2013, one participant passed away (GMFCS 1); and, in 2015, one participant (GMFCS 1) moved outside the residential care facility. In addition, three participants could not participate regarding the performance tests for the entire ten-year period: from 2009, one participant (GMFCS 2) was no longer able to carry out the performance tests due to physical complaints; from 2012, the informed consent was withdrawn by the participant's representative (GMFCS 1) with respect to the performance tests; and, from 2015, one participant (GMFCS 1) was no longer able to engage in the performance tests due to physical complaints.

The number of participants with zero to five available measurements over the ten-year period over pairs of years are displayed in Table 2 for GMFCS group 1 and in Table 3 for those with GMFCS 2.

Table 2. *Number of available measurements over a ten-year period over pairs of years yielding five measurement moments for GMGCS group 1 (N=36) for BMI, Wcf, mBBS and aSRT.*

Number of measurements	BMI	Wcf	mBBS	aSRT
0, N (%)	--	--	3 (8.3%)	--
1, N (%)	--	7 (19.4%)	5 (13.9%)	5 (13.9%)
2, N (%)	4 (11.1%)	7 (19.4%)	5 (13.9%)	8 (22.2%)
3, N (%)	3 (8.3%)	6 (16.7%)	8 (22.2%)	9 (25%)
4, N (%)	6 (16.7%)	7 (19.4%)	6 (16.7%)	5 (13.9%)
5, N (%)	23 (63.9%)	9 (25%)	9 (25%)	9 (25%)

BMI: Body Mass Index; Wcf: waist circumference; mBBS: modified Berg Balance Scale; aSRT: adapted Shuttle Run Test

Of the participants with GMFCS 1, 11 participants partly performed the aSRT and the 6MWD instead of executing the aSRT over the ten-year period.

Table 3. *Number of available measurements over a ten-year period over pairs of years yielding five measurement moments for GMGCS group 2 (N=19) for BMI, Wcf, mBBS and 6MWD.*

Number of measurements	BMI	Wcf	mBBS	6MWD
0, N (%)	--	1 (5.3%)	3 (15.8%)	--
1, N (%)	--	1 (5.3%)	1 (5.3%)	4 (21.1%)
2, N (%)	--	--	1 (5.3%)	2 (10.5%)
3, N (%)	--	1 (5.3%)	3 (15.8%)	--
4, N (%)	3 (15.8%)	2 (10.5%)	3 (15.8%)	4 (21.1%)
5, N (%)	16 (84.2%)	14 (73.7%)	8 (42.1%)	9 (47.4%)

BMI: Body Mass Index; Wcf: waist circumference; mBBS: modified Berg Balance Scale; 6MWD: 6-Minute Walk Distance test

The percentages with three to five measurement moments were, for participants with GMFCS 1, 88.9% for BMI, 61.1% for Wcf, 63.9% for mBBS and 63.9% for the aSRT. For

persons with GMFCS 2, these percentages were 100% for BMI, 89.5% for Wcf, 73.7% for mBBS, and 68.5% for the 6MWD.

For the entire group, the initial values (2008) for BMI and waist circumference were calculated, and these results are shown in table 4. The percentage who were overweight (BMI 25-30 kg/m²) of all of the participants was 29.6%; this percentage was 22.2% for men and 41.2% for women. Regarding obesity, 6.8% of all of the participants had a BMI ≥ 30 kg/m² of which 0% were men and 17.6% were women. The percentage of men with central obesity was 8% and 41.2% of women.

Table 4. *Percentages of participants with overweight, obesity, and central obesity in 2008, total (n=55) and divided into male (n=36) and female (n=19).*

Body composition	**Total**	**Male**	**Female**
BMI, mean, SD	24.6 ± 3.4	23.5 ± 2.4	26.3 ± 4.0
BMI < 25, %	63.6%	77.8%	41.2%
Overweight BMI 25-30, %	29.6%	22.2%	41.2%
Obesity BMI ≥ 30, %	6.8%	0%	17.6%
Waist circumference (Wcf), mean, SD	86.0 ± 9.5	86.0 ± 9.9	86.1 ± 9.1
Central Obesity Waist circumference (Wcf), %	-	8%	41.2%

BMI: Body Mass Index (kg/m²); Wcf: waist circumference (cm)

Body composition

Over the ten-year period, a mixed model analysis revealed that BMI remained reasonably stable for persons with GMFCS 1. As for those with GMFCS 2, a slight decrease (-1.2 kg/m² p=<0.05) was shown. However, waist circumference increased (+2.9 cm p=0.05) over this ten-year period for persons with GMFCS 1 while it remained quite stable for the GMFCS 2 group.

Participants classified in GMFCS Level 2 had lower BMI compared to those with GMFCS Level 1, and we found that women had higher BMI than men (female: 26.3 kg/m², SD 4.0 and male: 23.5 kg/m² SD 2.4).

Physical fitness performance

Over this ten-year period, individuals with GMFCS 1 increased on mBBS with 3.7 points ($p<0.001$). From time effect 3, corresponding to 2012/2013, a significant increase in mBBS was observed. For persons with GMFCS Level 2, the mBBS remained reasonably stable with a slight increase especially at time point 3 (2012-2013) of 2.4 points ($p<0.05$) after which this increase slightly decreases in the consecutive years. The participants with GMFCS 2 had lower scores on mBBS compared to those with GMFCS Level 1.

The levels of the aSRT remained quite stable for the GMFCS group 1 over the ten-year period with an increase of 2.8 levels ($p<0.001$) in time effect 2 (2010-2011). This increase declined in the following years to the initial values. For the participants with GMFCS 2, the scores on the 6MWD increased by 31 meters over this ten-year period.

In our study group, body composition and physical fitness levels remained stable for a long-term period with a slight improvement on mBBS and an increase of waist circumference for the GMFCS Group 1.

Table 5. *Time effect on outcome variables BMI, Wcf, mBBS and aSRT for GMFCS group 1.*

GMFCS-level 1 (n=36)	**Body composition**						**Physical fitness performance**					
	BMI			**Wcf**			**mBBS**			**aSRT**		
	b	CI 2.5% - 97.5%		b	CI 2.5% - 97.5%		b	CI 2.5% - 97.5%		b	CI 2.5% - 97.5%	
Intercept	24.6	23.7	25.5	88.9	85.5	92.2	31.0	29.4	32.9	10.6	9.4	11.7
Time effect 2 (2-1)	0.0	-0.7	0.7	2.3	-0.3	4.8	-0.4	-2.0	1.1	2.8***	1.9	3.7
Time effect 3 (3-1)	0.0	-0.7	0.8	1.9	-0.4	4.2	3.4***	2.0	4.9	1.0*	0.0	2.0
Time effect 4 (4-1)	-0.1	-0.9	0.6	2.9**	0.9	4.9	3.4***	1.9	5.0	0.0	-1.2	1.2
Time effect 5 (5-1)	-0.3	-1.0	0.5	2.9*	0.8	5.1	3.7***	2.2	5.2	0.2	-1.0	1.3

BMI: Body Mass Index (kg/m²); Wcf: waist circumference (cm); mBBS: modified Berg Balance Scale (points); aSRT: adapted Shuttle Run Test (level); ID: Intellectual Disability; GMFCS: Gross Motor Functioning Classification System; b: Estimated coefficient; CI: Confidence Interval; * p < 0.05; **p < 0.01; ***p<0.001

Table 6. *Time effect on outcome variables BMI, Wcf, mBBS and 6MWD for GMFCS-group 2.*

GMFCS-level 2 (n=19)	**Body composition**						**Physical fitness performance**					
	BMI			**Wcf**			**mBBS**			**6MWD**		
	b	CI 2.5%	97.5%	b	CI 2.5%	97.5%	b	CI 2.5%	97.5%	b	CI 2.5%	97.5%
Intercept	23.6	22.1	25.1	85.6	80.9	90.2	24.5	21.8	27.0	325.2	276.0	374.2
Time effect 2 (2-1)	-1.4*	-2.5	-0.3	-3.2*	-5.7	-0.6	-0.2	-2.2	1.8	14.0	-29.2	57.4
Time effect 3 (3-1)	-1.4*	-2.5	-0.4	-1.6	-4.0	0.9	2.4*	0.6	4.1	21.1	22.0	64.4
Time effect 4 (4-1)	-1.2*	-2.3	-0.1	0.0	-2.4	2.4	1.3	-0.6	3.2	2.6	-43.7	49.2
Time effect 5 (5-1)	-1.2*	-2.3	-0.1	0.6	-1.8	3.0	1.1	-0.7	2.9	31.0	-13.9	76.3

BMI: Body Mass Index (kg/m²); Wcf: waist circumference (cm); mBBS: modified Berg Balance Scale (points); 6MWD: 6-Minute Walk Distance test (m); ID: Intellectual Disability; GMFCS: Gross Motor Functioning Classification System; b: Estimated coefficient; CI: Confidence Interval; * $p < 0.05$; ** $p < 0.01$; *** $p<0.00$

Discussion

The purpose of this study was to gain insight into changes in the physical fitness levels of persons with SPIVD and GMFCS Levels 1 and 2 over a long-term period. Our results show that body composition and physical fitness levels remained stable or improved slightly (mBBS for GMFCS 1) during this ten-year period with waist circumference for the GMFCS 1 group as the only exception.

Our results indicate that BMI remained reasonably stable over the ten-year period for the entire group in which a slight decrease in BMI was observed for the participants with GMFCS 2. This is different compared to the general population in which, with the increase of age, BMI also increases as well as the percentage of those who are overweight and obese for both men and women.[37] Unlike the older persons with ID and the Dutch general population aged 50 to 70 years, the participants of the present study show a lower percentage of men being overweight (SIVD; 22.2% - ID; 39.2% Dutch General; 47.7%) compared to women (SIVD; 41.2% - ID; 37.1% - Dutch General; 35.3%) and, similar to the comparative studies, the percentage of women being obese (SIVD; 17.6% - ID; 38.0% - Dutch General; 14.8%) is higher compared to men (SIVD; 0% - ID: 13.7% - Dutch General; 13.2%) respectively.[30,38] Also, women with SIVD have a higher mean BMI (26.3 kg/m² SD 4.0) with respect to men (23.5 kg/m² SD 2.4) at the beginning point in 2008. This higher BMI for women compared to men deviates from the general population,[37] however, it is the norm for persons with ID.[39] The stable BMI and the lower percentage of obese individuals with SIVD (6.8%) compared to persons with ID (25.6%)[30,38] may be clarified by the severity of the ID and additional visual disability; all food and beverages are provided by the direct support persons of the residential care facility, and there are only minimal opportunities to obtain other foods or drinks. This is different for persons with less severe mental disabilities who more independently determine their diet. However, our research group is also relatively small compared to the comparative studies. Participants classified in GMFCS Level 2 had a lower BMI compared to those with GMFCS Level 1. An explanation of the higher percentage of individuals with GMFCS 1 who are overweight might be that the degree of dependence on the amount of food and beverage intake within a residential care facility is less due to their motor abilities and possibly also to their cognitive possibilities.[5]

Regarding waist circumference, our results indicate an increase over the ten-year period for persons with GMFCS 1 as the BMI for those with GMFCS 1 remained stable. Waist circumference is an indicator of abdominal fat, and it is an important predictor of health risks[40] which makes it an important issue to focus on in the residential care facility. In our participants, 21.4% have central obesity (Wcf males > 102 cm, females > 88cm) which is not as high as when compared to older persons with ID (43.7%) as well as to the Dutch general population aged 50 to 70 years (43.9%).[37,41] However, it has been shown that the percentage of women having central obesity is higher compared to men for both older persons with ID and the older general population as well as for the participants in this study. The increase of waist circumference over the ten-year period for the GMFCS 1 group and the percentage of women having central obesity compared to men emphasizes the importance of monitoring weight and waist circumference especially in women.

Our results indicate that mBBS as an outcome variable of physical fitness increased for persons with GMFCS Level 1 and that mBBS scores remained reasonably stable for persons with GMFCS Level 2. Participants with GMFCS Level 2 had lower scores on mBBS compared to those with GMFCS Level 1. According to the GMFCS classification, participants with level 1 can generally walk without restrictions and may have better balancing skills compared to participants with level 2 who can walk with slight restrictions.[14,15] The increase of mBBS can possibly be explained by the fact that, in 2011 and 2012, a number of intervention studies were conducted for improving balance in which both persons with GMFCS Level 1 and level 2 participated. Also, in 2011, the direct support in the residential care facility was focused on the daily practice of healthy physical activity and healthy nutrition of their residents. There was no negative effect of time on the scores of mBBS scores.

The results of aSRT for persons with GMFCS 1 remained virtually stable. In 2010-2011, an increase of 2.8 levels was seen which declined in the following years to the initial values. This can possibly be explained by the intervention programs and the policy of the residential care facility as mentioned in the discussion of the mBBS. Our data showed that, of the participants with GMFCS 1, 11 participants partly performed the aSRT and the 6MWD instead of executing the aSRT over the ten-year period. It is not clear what caused these changes in testing. It could be that the aSRT was too extensive for these

participants to perform. In that case, a recommendation would be to reassess the GMFCS classification of these participants to determine whether this has possibly changed in recent years.

The results of 6MWD for persons with GMFCS Level 2 increased by 31 meters. However, Oppewal and colleagues found that cardiorespiratory fitness levels of persons with ID do decrease with age, although these decreases may be less steep than in the general population.[42] The absence of a decline in the cardio respiratory fitness (aSRT and 6MWD) might occur because the scores on these physical tests are already very low as a starting value. In this study, the mean distance on the 6MWD was 336 meters (SD 92) over ten years (87 measurements) and, in another study with persons with SIVD, a mean distance of 389 meters (SD 107) was found.[10] This corresponds to averages of persons with COPD (369 m SD 18)[43] where individuals with heart failure had an average of 419 meters (SD 120)[44] and the mean distance of healthy elderly persons was 631 meters (SD 93)[45] The results of our study on 6MWD are comparable or somewhat lower than for persons with specific (chronic) health conditions. These low scores indicate a low functional exercise capacity of persons with SPIVD and GMFCS 2 which has an influence on their daily life. Regarding the scores on the aSRT for the GMFCS 1 group, it is difficult to compare the achieved levels with other groups because it concerns a specifically adapted test for persons with SPVID and GMFCS 1. However, overall studies showed that cardiorespiratory fitness levels for persons with ID are low compared to their peers without ID[43] and that persons with SPIVD walk at a slower pace compared to their same-aged peers without severe/profound ID.[5]

A limitation of this study is the relatively small sample size and the number of missing measurements over the course of ten years. However, it seems unlikely that this has influenced the results of the analysis by mixed modeling as no participants were excluded due to not having completed all of the measurements. It seems that there was enough data to keep track of the course of physical fitness levels of persons with SPIVD and GMFCS 1 and 2 levels over a long-term period.

In conclusion, for persons with SPIVD and GMFCS-levels 1 and 2, body composition and physical fitness levels remained stable or improved slightly over a long-term period where an increase in waist circumference for persons with GMFCS 1 and a higher percentage of

women being obese compared to men was observed. Low cardiorespiratory fitness levels were determined for persons with SIVD.

For future research, it is recommended to repeat a comparable study with a larger group of this population and to measure in decades to investigate the changes in body composition and physical fitness with aging for persons with SIVD in order to compare these results with aging in the general population.

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Supporting information

Appendix A: The modified Berg Balance Scale (mBBS)

Appendix B: The adapted Shuttle Run Test (aSRT)

Appendix C: The adapted Shuttle Run Test-GTX (aSRT-GTX)

Appendix D: The six-minute walk distance test (6MWD)

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Appendix A

The modified Berg Balance Scale (mBBS)

The mBBS is an adjusted scale that has been proven to be a feasible and reliable test for persons with intellectual and visual disabilities (IVD).[32] The original BBS consists of 14 items,[46] however, for persons with IVD, some of these tasks were too difficult to perform, for example, tandem standing, reaching forward while standing, turning one's trunk while feet are fixed, and standing with eyes closed.[32] Therefore, the protocol was slightly modified by excluding these four components and adding the following two new items; walk on a thin line and walk on a gym bar (width 30 cm, 40 cm above the floor). These two items were added because the participants did these tasks during the gymnastics exercise and, as a result, were familiar with them.[32] After determining the feasibility and the test-retest reliability, the items walking on a thin line and walking on a gymnastics beam (width 30 cm, 40 cm above the floor) were excluded because these items were not feasible or reliable.[32] As a result, the final mBBS consists of ten test items which are shown in Table 1 below.

Table 1. *Ten test items of the modified Berg Balance Scale.*

Number	Test item
1	Sitting unsupported
2	Change of position: sitting to standing
3	Change of position: standing to sitting
4	Transfers
5	Standing unsupported
6	Standing with feet together
7	Turning 360 degrees
8	Retrieving objects from floor
9	Standing on one leg
10	Walking on a gymnastic beam

The performance on each of these items is scored on a 5-point ordinal scale (0-4 points) whereby a score of 0 denotes the inability to perform a task and a score of 4 the ability to complete the task according to the established criterion. The maximum mBBS score is 40 points. If a participant did not understand a task, it was excluded from the total score.

The feasibility of the mBBS was sufficient for persons with SPIVD with a percentage of success measurements of 92% having sufficient test-retest reliability (ICC 0.95). [32]

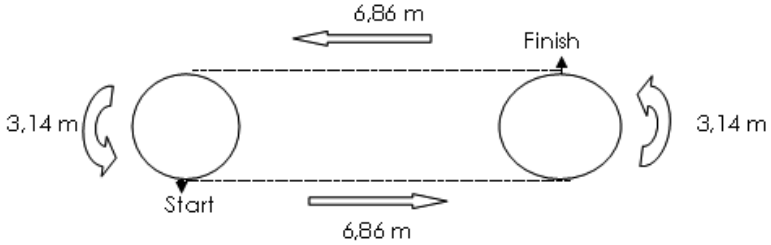
Appendix B

The adapted Shuttle Run Test (aSRT)

Incremental speed walking tests are effective methods to determine the aerobic capacity of both healthy individuals and persons with chronic health conditions.[33,34] To perform these tests, participants must walk or run between two markings (start and finish) at a distance of ten meters and a certain incremental speed determined by a signal played by a CD player.

The start speed of the adapted Shuttle Run Test (aSRT) was 3 km/h which was increased every minute by 0.25 km /hour.[11] Any increase in speed was called a step. At the time the test was stopped, the number of successfully completed steps represented the participant's level of aerobic capacity. The course of the aSRT consisted of an oval curve with two markings at the start and finish and was located in a gymnasium. (Figure 1, shown below). The participants walked between these two markers that demarcated the ten-meter course at an established incremental speed determined by an audio signal played from a standard CD player. The instructors accompanied all of the participants to help them adjust their pace to the audio signal and to maintain a minimal stress level for them. The adjustments to the course and the accompaniment of the participants were necessary due to the intellectual disability combined with visual impairment. At the end of each step, the participants were told to walk a little faster. The test was finished when participants were on two consecutive paced signals more than 1.5 m away from the end marker.

The feasibility of the aSRT is sufficient for persons with SPIVD and GMFCS-level 1 with a percentage of success measurements of 96%.[11] The reliability of the aSRT in persons with GMFCS 1 was sufficient with no significant differences between test and retest ($p<0.05$) and ICC for the test-retest 0.96 but not in persons with GMFCS-level 2.



Radius (R)=1 Meter
Distance between Start and Finish (half a round) = 6.86 m + ½ (2πR) = 6.86 + 3.14= 10 m

Figure 1. *Course aSRT*

However, the aSRT performed on the ground has limited validity being that the purpose of the test is to measure HRpeak.[16] Therefore, it was adapted to a treadmill protocol (GTX).[11] This test is a feasible, reliable, and valid way to determine HRpeak as well as the number of levels attained for persons with SPIVD and GMFCS-level 1.[11]

Appendix C

The adapted Shuttle Run Test-GTX (aSRT-GTX)

Participants walked on a treadmill with a starting speed of 3 km/hour. Every minute, the speed was increased by alternating steps of 0.3 and 0.2 km /hour to reach the next level. These levels were comparable to the levels of the aSRT.[11] The test leader had pre-programmed the treadmill with the GXT-protocol. All of the participants practiced walking on the treadmill at least twice before being tested. The specially trained gymnastics instructor accompanied the participant to the treadmill and attached the safety cord. The gymnastics instructor explained the procedure. To ensure safety, the instructor positioned himself behind the participant, with a foot on each side of the treadmill. The test administrator checked the watch and stayed one meter on the side of the participant during the entire test procedure. The treadmill (GTX) test was performed in a gymnasium where other clients were doing workouts. Once a week, the treadmill was calibrated to guarantee reliability. Participants continued the test until volitional exhaustion. The test was finished in three possible ways: when the participant insisted on stopping or refused to continue, when the predicted HR_{peak} was obtained,[47] or when the safety pin was pulled.

The level maintained during the last full minute was counted as the highest attained level.

The feasibility of the GTX on the treadmill was sufficient for persons with SPIVD and GMFCS-level 1 with a percentage of success measurements of 86.6%.[16] The reliability of the GTX in persons with SPIVD and GMFCS-level 1 was previously reported as sufficient ($p<0.05$, ICC 0.95). The validity of the GTX for measuring cardiorespiratory fitness was found to be sufficient.[16]

Appendix D

The six-minute walk distance test (6MWD)

The six-minute walk distance test (6MWD) is a reliable test to measure the functional exercise capacity of participants with different health conditions.[43,45] While performing the 6MWD, the participants are required to walk as far as possible within a period of six minutes without running. The distance covered during the test, measured in meters, was used as the outcome measure.

The 6MWD test was executed on a 36-meter course (Figure 2, shown below) located in a gymnasium. The participants walked six minutes at a self-chosen pace and attempted to cover as much distance as possible without running. Gymnastics instructors accompanied the participants to help them find their way. This adaptation was necessary due to the intellectual disability combined with visual impairment. The participants were encouraged in a standardized way. The total distance covered measures a participant's level of functional exercise capacity.

The feasibility of the 6MWD test was sufficient for persons with severe or profound intellectual and visual disabilities (SPIVD) with a percentage of success measurements of 96%.[11] The reliability of the 6MWD in these persons was sufficient (ICC 0.92) with no significant differences between test and retest ($p<0.05$).[11]

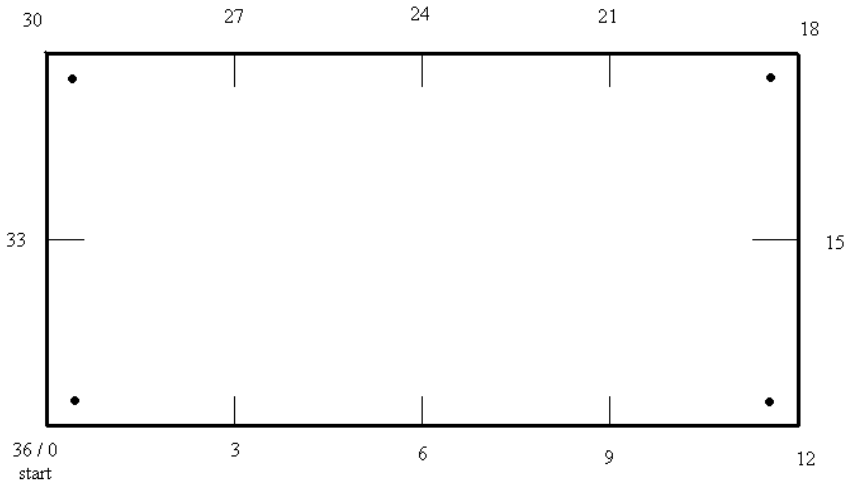


Figure 2. *6MWD course, total distance of 36 meters*